Evaluation of Patient Provider Support Agency (PPSA) implementation & Gender specific issues of tuberculosis patients of private sector in Patiala

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CERTIFICATE OF SUPERVISION

This is to certify that I will supervise the Thesis /Research work of Mr. Sukhwinder Singh entitled as **"Evaluation of Patient Provider Support Agency(PPSA) implementation & Gender specific issues of tuberculosis patients of private sector in Patiala".** The synopsis of which is enclosed herewith, for the research work to be done during the study of Doctor of Philosophy. (Social Work) course of the candidate.

The synopsis is prepared and submitted under my consent.

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DECLARATION

I hereby affirm that the work **"Evaluation of Patient Provider Support Agency (PPSA) implementation & Gender specific issues of tuberculosis patients of private sector in Patiala"** presented in this synopsis is exclusively my own and there are no collaborators. It does not contain any work for which a degree/diploma has been awarded by any other University/ Institution. All the ideas and references have been duly acknowledged.

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a. Introduction

The National Tuberculosis Elimination Program (NTEP) is the public health initiative of the Government of India. India has been engaged in TB control activities for over 50 years and yet TB continues to be India's important public health problem. TB kills an estimated 480,000 Indians every year and more than 1400 every day. However, despite robust public health interventions, one of the reasons that TB burden continues to remain high is the lack of effective publicprivate engagement. In India, the private sector is the preferred first point-of-care for TB patients and the current scale of public-private sector engagement is insufficient to effectively contribute towards addressing the TB burden. Currently private sector engagement challenges include: under reporting, under-diagnosis, diagnostic delays, irrational and non-standardized treatment regimens etc. It is critical to engage India's vast private sector to effectively implement the Standards of TB care (STCI). Additionally, nearly half a million patients go "undiagnosed" or "missing" in India as the private sector less notify the public sector about its TB cases even though it is mandated by the government. PPSA is an agency to manage end to-end private-sector engagement and augment NTEP's capacity to monitor and manage the needs of private-sector patients. It has been recommended in NTEP as an effective model to reduce the burden of TB in India. PPSA is a model under which a third-party agency/NGO is selected by a state/ city/district NTEP unit to engage private-sector doctors treating patients of TB and provide end-to-end services, such as diagnosis, notification, patient adherence and support, and treatment linkages.

The PPSA project is ongoing in the two districts of Punjab i.e. Amritsar and Patiala, covering 4.39 million of population. It aims to set up an effective and sustainable structures to strengthen existing systems to increase case notifications and extend eminence TB care to patients seeking care in the private sector. The project engages all types of private providers ranging from standalone qualified doctors to pharmacies, pathology labs and hospitals to ensure timely treatment access to the TB patients who seek care in private sector. Under PPSA project, private patients receive free, quality-assured diagnostic and treatment services to ensure cure while

minimizing out-of-pocket (OOP) expenses. The project provides patients with treatment adherence support by facilitating regular interaction between patients and providers; facilitates the provision of incentives by the NTEP to patients for nutritional support and to private providers for notification. Through these interventions, the project ensures access to diagnostics and treatment, notification, and improved treatment success rates.

In private sector, counseling and record of treatment is always a big challenge which leads to dropout and unsuccessful treatment outcome. This study will help to understand the working of PPSA program and gender specific issue of TB patients of private sector. It will outlay the problems faced by women during TB treatment and will help to evaluate the diagnosis and treatment being provided by the private sector doctors. Women are especially constrained by social norms which prevent prioritizing of their nutrition, health and wellbeing. Under nutrition, their role as caretakers and the use of solid fuel for cooking puts women at risk for TB. Men are at greater risk of developing TB due to their employment in mining, quarrying, metals and construction industries. Stigma and discrimination are major impediments to treatment adherence, mainly among unmarried women, newly married women and the elderly. The concept builds upon the various insights that have been undertaken by different researchers in the field of Tuberculosis.

b. Statement of the Problem/Research Problem

Women account for three million of the estimated seven million people affected by Tuberculosis (TB) every year. TB remains among the top five leading causes of death among adult women globally. Although more men are affected by TB, women experience the disease differently, and gender disparities play a significant role in how men and women access healthcare in the public and private sectors. Even so, little is known globally and in India about the different biological and social factors that affect the incidence, disease manifestation, progression and health seeking behavior of persons suffering from TB, their response to treatment and treatment outcomes. In India, the incidence of TB in 2016 was 2.76 million, with women

accounting for 40% of the new cases. The male to female ratio for TB stood between 1.07 to 2.25 in 2016. There is evidence of male to female ratios of persons suffering from TB varying between 30 to 40% from across the world. This suggests that the differences in incidence of TB may be due to significant social factors such as exposure to the infection and access to health care are at play too. The substantial gap in TB incidence between men and women could also be due to under-reporting of the disease among women. Qualitative studies and interactions with program managers and patient advocates brought up a range of issues including stigma, barriers to access health services and neglect of the disease among populations who do not conform to society's gender norms.

Although standardized TB care in India is delivered by public sector through National Tuberculosis Elimination Programme (NTEP), private sector is the first point of contact for 50-80% of patients. As highlighted in the National Strategic Plan (NSP), the current scale of private sector engagement is insufficient relative to its size and contribution to TB care. There are gaps across the patient care cascade on account of under reporting, diagnostic delays, irrational and unsupported treatment and catastrophic out of pocket expenditure to patients. These challenges have made it difficult for programme to effectively engage with the private sector as evidenced by limited uptake of RNTCP Public-Private Mix (PPM) schemes. Other areas like absence of policy for private sector engagement; vacant HR posts, limited capacities and resources at state and district level; insufficient tariff norms for service delivery under the existing PPM schemes and challenging financial mechanisms of payments under PPM schemes also make engagement difficult. The NTEP has worked around these challenges by mandating TB notification, developing guidelines for private sector engagement, provisioning PPM coordinators at district level, prioritizing and increasing fund allocation for private sector under NSP including provisioning of Direct Benefit Transfer (DBT). However, gaps remain and in order to meet the ambitious National Strategic Plan (NSP) 2017-25 targets, intensified continuous engagement with private sector is required. As per the PMO commitment India has set the target of TB elimination by 2025 which is five years ahead then the global target.

The robust assessment of Patient Provider Support Agency (PPSA) is of vital importance in order to understand current implementation practices, barriers and gender specific issues faced by private sector TB patients in Patiala.

c. Literature Review

There is a wide range of literature that explores gender issues in TB, sex-wise epidemiology of TB, how TB affects women, socio-cultural aspects of TB, community responsiveness and gender responsiveness of TB programs, access to health care with a community and gender perspective and the impact of TB on the health of women and marginalized groups. We reviewed research, policy and program related reports from governmental and non-governmental sources, peer reviewed journals and UN publications, keeping the above-mentioned themes in focus and concentrated on those specifically pertaining to India. Some important papers studying global and South Asian evidence were also reviewed. For this purpose, a key word search was undertaken using the key words 'tuberculosis' and 'gender' and 'India' starting from the year 2000 till date. The database covered was PubMed. 35 papers were downloaded and the abstracts studied using these criteria. At the same time other sources of reports and policy papers were researched mostly through papers suggested by TB and public health experts whom we interviewed, including a database generated by an Indo-Canadian research initiative on 'Gender and TB' by Prof. Bilkis Vissandjee of Montreal University and Prof. Lakshmi Lingam of Tata Institute of Social Sciences. This study highlighted the gender specific issues of Mumbai and various issues of stigma associated with tuberculosis. These issues may be similar for Punjab.

A study of gender differentials in the prevalence of tuberculosis based on NFHS-2 and NFHS-3 data was evaluated which says that overall prevalence of TB combined for urban and rural areas was 432 per lakh (1 lakh=100,000) in NFHS-2 and 418 per lakh in NFHS-3. This decline was not statistically significant ($\chi 2$ =1.19; P0 = 0.275) as shown in both the NFHS surveys, the prevalence of TB among males

is found to be higher than the females [Table 2]. The gender gap being 145 per lakh in NFHS-2 has increased to 217 per lakh in NFHS-3, the difference being statistically significant ($Z=2.747$, $P<0.05$).

A further short-listing of papers was done based on their specific substantial contributions made to the understanding of gender and TB.

d. Gaps in research

Various studies which explored stakeholders' responses of gender specific issues and tuberculosis recommended a need to expand the number of policy studies in developing countries so as to better understand the environments in which patient may get the good services. Involving health policy makers, program manager, Private providers and patient's perspectives can help strengthen the implementation and suggest mid way corrections in the policies aiming to strengthen the early diagnosis and care with standardized TB treatment protocols. Additionally, there are operational challenges have been reported pertaining to the insufficient staffing and no mechanisms for regular monitoring of achievement against programme goals and objectives and ensured resources allocation along with effective disbursement.

e. Needs of the study

This is first study in Patiala, Punjab which will showcase the private sector engagement and also provide the key gender based issues being faced by the private sector patients. There is a growing body of evidence that women may be diagnosed late or not diagnosed at all; that TB presents differently among women, making diagnosis among them more difficult; that there are various socio-cultural barriers which hamper women's access to diagnostic facilities. A Rapid Assessment of Gender and Tuberculosis women may be at added risk of the disease in certain stages of their lives and on account of their role as caregivers in the family. The NTEP has largely concentrated on identifying and treating the infectious form of TB namely sputum positive pulmonary TB and the diagnosis of Sputum negative and Extra-Pulmonary cases of TB (EPTB) is often missed.

In recent times, more girls and women are being diagnosed with TB due to increased access to healthcare and the deployment of newer diagnostic technologies like CBNAAT. TB among children remains under-diagnosed again due to the different presentation of TB in this age group and the challenges in diagnosis. Detecting all forms of TB, particularly among women, is necessary to progress towards the targets of the End TB Strategy. Malnutrition substantially increases risk of TB disease in women and results in poorer outcomes mostly related to poorer adherence to treatment. Over half of all women in the country are anaemic and one in five are underweight. Women delay seeking care for ailments because of a high burden of household work combined with the deprivation of health literacy, mobility, access to resources and decision-making powers. We found a high level of stigma associated with a TB diagnosis among both unmarried and married women. Unmarried women were anxious that they might not get married if they had TB. Consequently, families hid the diagnosis, marrying off the women and later sending them to a relative's home to begin treatment. The women were forced to continue TB treatment clandestinely after marriage. For already married women, the fear of being divorced or being sent back to their natal family is an obstacle to accepting TB diagnosis and treatment. These factors considerably influence TB case detection and adherence to treatment, and need to be addressed.

This study will include the testimonials of the private providers, chemists, labs and private sector patients so a clear picture of service providers and beneficiaries will be shown. In India, many private sector studies have been conducted and which showed the positive impact of the collaboration. Hence with this background, we are proposing a study to evaluate the services and barriers of PPSA in Patiala considering as a representative district and gender specific issues of tuberculosis patients who opt for private sector.

f. Objectives:

a. To identify barriers for accessing TB services by Girls and Women in Patiala in private facilities.
b. To map the gender specific issues of private sector TB patients in

Patiala.

c. To assess the gap between the providers (Doctor, Chemists, Labs) and the beneficiaries (TB Patients).

g. Scope

The study will be conducted in district Patiala, Punjab. During study some out of district TB patients may be included based on the treatment initiation facility.

h. Delimitation of study:

The study will be qualitative in nature. The identification of barriers and services will be subjective, without incorporation of an objective data.

i. Research questions:

What are the barriers of accessing TB services by Girls and Women in Patiala in private facilities. ?

What are the gender based challenges being faced by private sector TB patients?.

What are the gaps between the providers and the beneficiaries in Private sector TB program?

j. Research Hypothesis: Null hypothesis

The introduction of mandatory gazette TB notification has no effect on private sector engagement in Patiala.

k. Research Design

1. **Research methodology**: This will be a qualitative study design. The study sampling will follow purposive sampling. The study population will include government officials working in the National Tuberculosis Elimination program, Punjab. This will include the officials of State TB Cell, Punjab and staff of district TB cell, Patiala. The external stakeholders which includes Private doctors, chemists, Labs representatives and TB patients of private sector.

The in-depth interviews will be conducted with above mentioned stakeholders. The participants will be asked questions about the status of TB program (related to their professional domain) and focus will be on identification of existing services, effectiveness and barriers. The gender based issues will be explored.

2. Area of study

The study will be conducted in the district Patiala of Punjab state.

3. Sample selection and sampling technique

The sample will be recruited using convenient sampling as this will be a qualitative study. Thus, the participants interested to speak up will be able to provide relatively comprehensive information. Participants will be recruited till the saturation is achieved with the information being obtained.

4. Tools

An in-depth interview guide will be prepared based on the implementation components of NTEP. The guide will be pretested and modified for finalization based on the feedback obtained. The recorder will be used to record the feedback and query of the respondent.

5. Measurement and scaling

Other than the qualitative interviews, the observational checklist based on the measurable components of NTEP will also be prepared to gather information on the extent of institutional mechanism, activities and implementation of components of PPSA.

6. Data processing and analysis

The mode of data collection (paper-based/digital) will be decided before initiating the survey. After data collection, all the data will be fed in MS Excel for data cleaning. The data gathered through observational checklists will be assessed quantitatively.

7. Testing hypothesis

Alternative hypothesis: The PPSA project will reduce the gap between public and private sector and help to provide free diagnostic services to the patients.

8. Expected outputs

- Evaluation of activities covered under the NTEP
- Effectiveness of services provided under PPSA
- Information regarding gender based issues
- Reporting mechanism under PPSA
- Information on the barriers of implementation of PPSA

9. Relevance of expected results

The expected outcomes will help in understanding the current status of implementation of PPSA and barriers of accessing TB services by Girls and Women in Patiala in private facilities. It will give the idea of gender based challenges being faced by private sector TB patients and identify the gaps between the providers and the beneficiaries in Private sector TB program. Indirectly, it will further help in constitute the counseling mechanisms for TB patients and providers so that better services should be provided.

10. Timelines

Activity	**Month**					
	1	**2**	**3**	**4**	**5**	**6**
Development of in-depth interview tool and observational checklist						
Ethical Approval						
Administrative Approval						
Identification of the Participants						
Data collection						
Data cleaning/ translation and Analysis						
Report writing						
Dissemination of results						

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